

# Carers Census 2017

Specification for data collection on:

- **Adult Carers Support Plan / Young Carers Statement**
- **Support for carers**

to provide baseline data for 2017-18 and to monitor the Carers Act being implemented on 1 April 2018.

## Carers Census 2017

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# Carers Census 2017

## Specification for Carers Census 2017 data collection

### Version history

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0.1	10/5/2016	Draft	Martin Devine		Initial draft
0.2	26/5/2016	Draft	Martin Devine		
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0.4	7/7/2016	Draft	Julie Rintoul		Sent to working group
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0.6	19/08/2016	Draft	Julie Rintoul		Incorporating comments from Mike Brown, Social Work Scotland and Chair of Short life Working Group

# Carers Census 2017

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# Carers Census 2017

## Introduction

### Why is the Scottish Government collecting this information?

The census collects information which will be used by the Scottish Government, COSLA and Local Authorities to monitor the implementation of the Carers Act. The Carers Act will be implemented on the 1<sup>st</sup> April 2018 but it is important to collect data for the year prior to implementation so that the impact of the Act can be assessed. Analysis of this information will let all stakeholders understand how the Act changes the number of requests for assessment, the number completed, and the types of support which carers require. It will help the Scottish Parliament, the Scottish Government, carers' organisations and other stakeholders, understand how the new Act is making a difference to the lives of carers across Scotland. The Census will also help discussions on future funding needs for support to carers.

### Who will use information from the census?

We expect statistical analysis from the census to be used by many different people and organisations such as:

- Scottish Government
- COSLA
- Local Authorities
- Integration partnerships
- NHS Boards
- National Carers Organisations
- Social Work Scotland
- Third Sector
- Carers
- Academics
- Approved researchers with an interest in Carers and Social Care
- Members of the Public
- MSPs

# Carers Census 2017

## Who can I contact if I want to ask questions on the guidance notes?

Julie Rintoul

Health & Social Care Analysis

Scottish Government

Telephone: 0131 244 5366

e-mail: [SWStat@scotland.gsi.gov.uk](mailto:SWStat@scotland.gsi.gov.uk)

## Who can I contact if I want to ask questions on IT/ ProcXed.Net?

John McLean

ScotXed Unit

Scottish Government

Telephone: 0131 244 8492

e-mail: [ScotXed.ITSupport@gov.scot](mailto:ScotXed.ITSupport@gov.scot)

## When will the census happen?

xxx

## When do I have to submit the data by?

xxx

## What is the purpose of this document

These notes have been prepared by the Scottish Government to assist local authorities with the collection and submission of data.

# Carers Census 2017

## Who should be included in the census?

Data should be returned for all carers known to local authorities (and other organisations who provide assessment and/or support for carers on behalf of local authorities).

This includes all persons who meet any of the following criteria:

- have had an assessment or review of their needs as carers during the reporting period; or
- have been offered an ACSP or YCS during the reporting period (including those who turned down the offer of assessment); or
- have requested an ACSP or YCS during the reporting period; or
- have received one or more of the support services in the list below at any time during the reporting period; or
- care for a person who has received respite or replacement care at any time during the reporting period; or
- are known by the local authority to be carers, but do not come under any of the groups listed above (e.g. a carer who was assessed prior to the reporting period, but is not receiving support because they did not meet the eligibility criteria)

For the 2017-18 data collection prior to the introduction of the Carers Act, Adult Carer Support Plan / Young Carer Statement should be interpreted as your current Carers Assessment process.

## Support services

A carer who has received one or more of the services listed below should be included in the data returned.

- short breaks or respite
- information and advice
- practical support (e.g. transport, equipment, adaptations)
- counselling or emotional support
- training or learning
- advocacy services
- help applying for carer's allowance and other financial assistance
- a "carers payment" made by a local authority or IJB

# Carers Census 2017

## Do Scottish Government collect any other information on carers?

Carers who receive self-directed support to purchase services or support are currently included in the Social Care Census. The client group categories in the Social Care Census allow identification of whether someone is a carer as well any disabilities or long-term conditions. The full data collected in the Social Care Survey can be found at:

<http://www.gov.scot/Topics/Statistics/Browse/Health/SocialCareSurvey> and includes:

For each carer:

- postcode
- date of birth
- gender
- ethnic group

If receiving Self-Directed Support:

- SDS options chosen
- SDS start date
- SDS end date
- SDS total package value
- Assessed needs e.g. short break

Note that information on SDS is not collected in this census but can be linked to the Carers Census using the unique identifier provided for the carer.

# Carers Census 2017

## What is collected in the Carers Census?

### For each Carer:

- Local Authority code
- CHI number
- surname\*
- forename\*
- postcode
- date of birth
- gender
- ethnic group
- care hours
- care type
- care level

### For the person they care for:

- CHI number
- surname\*
- forename\*
- postcode
- date of birth
- gender
- ethnic group
- client group

### For Adult Care Support Plan / Young Carers Statement:

- source of referral for ACSP / YCS
- date ACSP / YCS requested / offered
- type of ACSP / YCS – new or review
- ACSP / YCS completed?
- date completed
- ACSP / YCS declined
- date declined
- ACSP / YCS joint assessment with cared for person
- is carer willing and able to care
- is carer eligible for support
- eligibility criteria
- carers support needs
- support provided / purchased by LA
- did review result in change to support
- what conditions would trigger a review

### For Young Carers Statement:

- responsible Authority for young carer
- extent to which responsible authority feels care provided by young carer is appropriate

\*required for data linking purposes if uniqueID is not provided consistently across Carers Census and Social Care Survey.

# Carers Census 2017

## Data Definitions for the Carers Census

**Carer:** An individual who provides or intends to provide care for another individual (the “cared-for person”), except where:

- the care is or would be provided under or by virtue of a contract, or as voluntary work.
- in the case of a cared-for person under 18 years old, to the extent that the care is or would be provided by virtue of the person’s age

[\(Section 1 of the Carers \(Scotland\) Act 2016\)](#)

**Young carer:** A carer who is either under 18 years old, or has reached age 18 while still at school, and is still at school.

[\(Section 2 of the Carers \(Scotland\) Act 2016\)](#)

**Adult carer:** A carer who is at least 18 years old, and not a young carer. [\(Section 3 of the Carers \(Scotland\) Act 2016\)](#)

**Following introduction of the Carers Act on 1 April 2018, the following terms are applicable:**

**Adult Carer Support Plan (ACSP):** This is a plan prepared by a responsible local authority setting out:

- (a) an adult carer’s identified personal outcomes
- (b) an adult carer’s identified needs (if any)
- (c) the support (if any) to be provided by the responsible local authority to an adult carer to meet those needs

[\(section 6\(1\) of Carers \(Scotland\) Act 2016\)](#)

**Young Carer Statement (YCS):** This is a statement prepared by a responsible authority setting out:

- (a) a young carer’s identified personal outcomes
- (b) a young carer’s identified needs (if any)
- (c) the support (if any) to be provided by the responsible local authority to a young carer to meet those needs

[\(section 12\(1\) of the Carers \(Scotland\) Act 2016\)](#)

## Carers Census 2017

**Responsible local authority:** The local authority for the area in which the cared-for person resides. ([Section 41 of the Carers \(Scotland\) Act 2016](#))

**Responsible authority:** In relation to a young carer, the responsible authority is:

- the health board in which the young carer resides, where the young carer is a pre-school child
- the local authority in which the young carer resides, where the young carer is not a pre-school child

([Section 19 of the Carers \(Scotland\) Act 2016](#), but please note the special cases in [Section 20](#))

A “pre-school child” is a child who:

- has not commenced attendance at a primary school, and
- if the child is of school age, has not commenced attendance at a primary school because the relevant local authority has consented to the child’s commencement at primary school being delayed.

([Section 36\(3\) of the Children and Young People \(Scotland\) Act 2014](#))



## Carers Census 2017

Variable Name	Description	Format/Values	Additional information
IDCarer	Unique identifier for the carer.	Numeric/Character	<p>This must be provided for all carers.</p> <p>The variable IDCarer must be unique to a particular client within the local authority. It may be the unique identifier used in the local authority's MIS or may be generated for the purposes of the data return. If the unique care ID is generated, it must be consistent to the client across <b>all datasets returned for the carers' assessment data collection</b> and the <b>Social Care Survey</b> and <b>repeatable over time. This is important to ensure that Carers can be identified as both providing care and receiving services.</b></p> <p>Where a carer appears in more than one dataset, they should have the same unique ID in each - this also applies to data relating to different years/quarters/etc. to allow for longitudinal analysis.</p>

## Carers Census 2017

Variable Name	Description	Format/Values	Additional information
CHI	<p>Community Health Index (CHI) number for the carer.</p> <p>The CHI is a population register, used in Scotland for health care purposes. The CHI number uniquely identifies a person on the index.</p>	10-digit number	<p>Optional at present as aware that not all local authorities store CHI number. Useful for data linkage projects involving anonymised social care data.</p> <p>The data provided will be one-way encrypted once the data has been uploaded to proxcd.net to protect patient privacy. This means that the Scottish Government will not be able to see the CHI number, but instead a string of numbers and characters.</p> <p>The encryption method used will be shared with the CHI Indexing teams at ISD Scotland and NHS Central Register to enable data linkage in future.</p>
Surname	Surname/family name of carer.	Character	Required for data linkage/matching/ longitudinal analysis if the council is unable to provide an IDCarer variable or CHI.
Forename	Forename/first name of carer.	Character	Required for data linkage/matching/ longitudinal analysis if the council is unable to provide an IDCarer variable or CHI.

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Variable Name	Description	Format/Values	Additional information
Postcode	The postcode of the carer's home address on the date that the assessment was offered/requested.	Standard postcode format, including space. e.g. AB12 3CD	<p>This must be provided for all carers. <b>Must be present and must be a full valid postcode.</b> Postcode will be used as a data quality check with IDCarer. It will also be used to create geography variables such as health board. Postcode can be used for future spatial analysis (e.g. distance carer lives from person they care for). Postcode will be removed from dataset used for statistical analysis. Raw data will be stored in a secure data warehouse.</p> <p>Used for data linkage/matching and geographical analysis.</p>
DateOfBirth	Carer's Date of Birth	DD/MM/YYYY format.	<p>This must be provided for all carers. Only month and year of birth will be passed to statisticians for analysis purposes. Full date of birth will be held separately by ScotXed for data linking purposes.</p> <p>Used for data linkage / matching and for analysis of data by age of carer.</p>
Gender	Gender of the carer.	1 - Male 2 – Female 99 - Not Known	<p>This must be provided for all carers. In future when question developed to identify transgender we may expand this question: <a href="http://www.gov.scot/Resource/0039/00393543.pdf">http://www.gov.scot/Resource/0039/00393543.pdf</a></p> <p>Used for data linkage / matching and for analysis of data by gender of carer.</p>

## Carers Census 2017

Variable Name	Description	Format/Values	Additional information
EthnicGroup	<p>Ethnicity of the carer.</p> <p>To allow analysis of carer data by ethnic group. The Scottish Government has a clear commitment to equal opportunities under the <a href="#">Equality Act 2010</a>.</p>	<p>01 - White</p> <p>02 - Mixed or multiple ethnic groups</p> <p>03 - Asian, Asian Scottish or Asian British</p> <p>04 - African, Caribbean or Black</p> <p>05 - Other Ethnic Background</p> <p>97 - Not Disclosed</p> <p>99 - Not Known</p>	<p>Ethnic group must be provided for all carers.</p> <p>The purpose of this item is to record the ethnic background of individuals, not nationality or country of birth.</p> <p>Code 97 (Not Disclosed) should only be used where the carer does not want their ethnic background to be recorded. In all other cases where no return has been made by the carer, please use code 99 (Not Known).</p> <p>All local authorities are asked to make reasonable efforts to ensure that ethnic background data are available for all clients.</p> <p>To allow analysis of data by ethnicity for equalities purposes. (LAs need to take impact of having protected characteristic(s) into account - Carers Act S8(2)).</p> <p>For more information on collecting ethnicity data see: <a href="http://www.gov.scot/Resource/0039/00394314.pdf">http://www.gov.scot/Resource/0039/00394314.pdf</a></p> <p>This information will enable a national picture to be built of the ethnic background of carers, and this in turn will inform policy development and help the Scottish Government to address identified needs and to deploy resources appropriately.</p>

## Carers Census 2017

Variable Name	Description	Format/Values	Additional information
CareHours	Number of hours of care that the carer provides in a typical week.	1 - up to 4 hours 2 - 5 - 19 hours 3 - 20 - 34 hours 4 - 35 - 49 hours 5 - 50+ hours 9 - Not Known	This must be provided for all carers and will be the hours of care recorded at the last assessment or review. Exclude any caring that is done as part of paid employment or formal volunteering. If the carer provides care for more than one person, this should be the total amount of care provided.  Provides information on the extent of care provided and impact on carer's life (Carers Act s9(1)(a))
CareType	Type of care that the carer provides.	1. Help with medication 2. Help with personal care 3. Help with shopping, cleaning, domestic tasks	This must be provided for all carers. (Multiple responses possible.)  Provides information on the extent of care provided and impact on carer's life (Carers Act s9(1)(a))
CareLevel	The level of care that the carer is willing to provide.	1 – Not willing to provide care 2 – Willing to provide current level of care 3 – Willing to provide less than current level of care 4. – Willing to provide more than current level of care	This must be provided for all carers.  Provides information on the extent of care that the carer is able and willing to provide (Carers Act s9(1)(b)). Willingness to provide care may be related to receiving more support.

## Carers Census 2017

### Cared-for person data

Section 9(1)(a)(i) of the Carers Act states that an ACSP must contain information about the nature and extent of the care provided or to be provided. This suggests that the data collected should contain information about the cared-for person as well as the carer, or the means to link carers assessment data to a cared-for person dataset (e.g. data from the Social Care Survey).

A Carer may care for more than one person. Multiple Cared for person records can be provided for each carer.

Variable Name	Description	Format/Values	Additional information
IDCarer	Unique identifier for the carer.	Numeric/Character	This must be provided for all carers and provides a link to the carer data collected in the section above. IDCarer will not be unique within the cared-for person dataset - for example, if a carer provides care to two people, that carer's IDCarer will appear twice in this dataset.
UniqueID	Unique identifier for the Cared for person	Numeric/Character	<p>This must be provided for all cared-for persons, and should be unique within the cared-for person dataset. If the cared-for person is already known to Social Work then this should be the same identifier used in the Social Care Survey.</p> <p>The cared-for person could also be a carer. Therefore the IDCarer and UniqueID variables should use the same unique identifier for each individual person to allow for identification of dual carer/cared for person relationships and to identify where there are multiple carers for one person or one person caring for multiple people.</p>

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Variable Name	Description	Format/Values	Additional information
CHICFP	Community Health Index number for the cared-for person.	10-digit number	<p>Optional at present as aware that not all local authorities store CHI number. Useful for data linkage projects involving anonymised social care data.</p> <p>The data provided will be one-way encrypted once the data has been uploaded to procxed.net to protect patient privacy. This means that the Scottish Government will not be able to see the CHI number, but instead a string of numbers and characters.</p> <p>The encryption method used will be shared with the CHI Indexing teams at ISD Scotland and NHS Central Register to enable data linkage in future.</p>
SurnameCFP	Surname/family name of cared-for person.	Character	Required for data linkage/matching/ longitudinal analysis if the council is unable to provide a UniqueID variable or CHI.
ForenameCFP	Forename/first name of cared-for person.	Character	Required for data linkage/matching/ longitudinal analysis if the council is unable to provide a UniqueID variable or CHI.
PostcodeCFP	The postcode of the cared-for person's home address on the date that the assessment was offered/requested.	Standard postcode format, including space. e.g. AB12 3CD	<p>This must be provided for all cared for persons. Must be present and must be a full valid postcode.</p> <p>Postcode will also be used to create geography variables such as health board. Postcode can be used for future spatial analysis (e.g. distance carer lives from person they care for). Postcode will be removed from dataset used for statistical analysis. Raw data will be stored in a secure data warehouse.</p> <p>Used for data linkage/matching and geographical analysis.</p>

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Variable Name	Description	Format/Values	Additional information
DateOfBirthCFP	Cared-for person's Date of Birth	DD/MM/YYYY format.	<p>This must be provided for all cared for persons. If exact date of birth is not known then an estimated year of birth can be given as 01/01/YYYY.</p> <p>Only month and year of birth will be passed to statisticians for analysis purposes. Full date of birth will be held separately by ScotXed for data linking purposes.</p> <p>For analysis of data by age of cared-for person and to explore age difference between cared for person and carer.</p>
GenderCFP	Gender of the cared-for person.	1 - Male 2 - Female 99 - Not Known	<p>This must be provided for all clients.</p> <p>For analysis of data by gender of cared-for person.</p>
EthnicGroupCFP	Ethnicity of the cared-for person.  To allow analysis of data by ethnic group. The Scottish Government has a clear commitment to equal opportunities under the <a href="#">Equality Act 2010</a> .	01 - White 02 - Mixed or multiple ethnic groups 03 - Asian, Asian Scottish or Asian British 04 - African, Caribbean or Black 05 - Other Ethnic Background 97 - Not Disclosed 99 - Not Known	<p>Ethnic group must be provided for all carers. The purpose of this item is to record the ethnic background of individuals, not nationality or country of birth.</p> <p>Code 97 (Not Disclosed) should only be used where the carer does not want their ethnic background to be recorded. In all other cases where no return has been made by the carer, please use code 99 (Not Known).</p> <p>All local authorities are asked to make reasonable efforts to ensure that ethnic background data are available for all clients.</p> <p>To allow analysis of data by ethnicity for equalities purposes.</p>

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Variable Name	Description	Format/Values	Additional information
ClientGroupCFP	Client group of the cared-for person.	01 - Dementia 02 - Mental Health Problems 03 - Learning Disability 04 - Physical Disability 05 - Addiction 06 - Palliative Care 08 - Problems arising from infirmity due to age 98 - Other vulnerable groups 99 - Not Known	At least one client group must be provided for all cared-for persons, and multiple client groups can be provided if applicable.  See Annex for descriptions of the client groups.  Provides (contextual) information on the extent of care provided and impact on carer's life (Carers Act s9(1)(a))  <i>Are these groups sufficient to cover all cared-for persons? (e.g. children with ADHD, cared-for person with a purely medical condition) - worth including a free text field to be completed if response is 'Other' to get more detail?</i>

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## Carers Census 2017

### Carer assessment data

Variable Name	Description	Format/Values	Additional information
IDCarer	Unique identifier for the carer.	Numeric/Character	This must be provided for all carers.
CASource	What was the source of the referral for an ACSP / YCS	1 - Requested by carer 2 - Social Work 3 - Health 4 - Carers Centre 5 - Other	Must be provided for all records.  To provide information of the number/ proportion of reviews offered and requested and to determine which bodies are promoting ACSP / YCS
CADate	Date that the carer assessment was requested/offered.	DD/MM/YYYY format (or whatever date format is appropriate).	Must be provided for all records.  To provide information about timescales for assessments and the distribution of requests/offers over the year.
CAType	Type of carer assessment.	1 - New 2 - Review / Re-assessment	Must be provided for all records.  To differentiate between new assessments and reviews or re-assessments - will give an indication of time between reviews (when combined with request/offer date).
CAComplete	Has the carer assessment been completed?	1 - Yes 0 - No	Must be provided for all records.  To provide information on the number/ proportion of assessments completed.

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Variable Name	Description	Format/Values	Additional information
CADateComp	Date that carer assessment was completed.	DD/MM/YYYY format.	<p>Only required if CAComplete = Yes - must be provided for all of these records.</p> <p>To provide information about timescales for assessments.</p>
CADeclined	Was the carer assessment declined?	1 - Yes 0 - No	<p>Only required if CAComplete = No - must be provided for all of these records.</p> <p>To provide information on the number/ proportion of assessments declined.</p>
DeclineDate	Date that the carer assessment was declined	DD/MM/YYYY format.	<p>Only required if CADeclined = Yes - must be provided for all of these records.</p> <p>To provide information about timescales for assessments.</p>
CAJoint	Was the ACSP/YCS carried out as part of a joint assessment with the cared-for person?	1 - Yes 0 - No	<p>Only required if CAComplete = Yes - must be provided for all of these records.</p> <p>To provide information about how assessment is carried out.</p>
CAWilling	Is the carer willing and able to provide care for the cared-for person?	1 - Yes 0 - No (Other options?)	<p>Only required if CAComplete = Yes - must be provided for all of these records.</p> <p>To give an indication of the proportion of carers who are not willing/able, as the people that they care for are more likely to need additional support in the future.</p>

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Variable Name	Description	Format/Values	Additional information
CAEligible	Is the carer eligible for support? (There will be eligibility criteria to be met in order for the carer to receive support - does the carer meet these criteria at the time that the assessment was completed?)	1 - Yes 0 - No	Only required if CAComplete = Yes - must be provided for all of these records.  To provide information about the number/ proportion of carers assessed to need support who are eligible.
Eligibility Criteria	The eligibility category applicable to the carer at time of assessment.	1. Critical 2. Substantial 3. Moderate 4. Low 5. None	<i>Guidance on eligibility criteria for carers is still being written</i>

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Variable Name	Description	Format/Values	Additional information
CASupportNeeds	The support needs of the carer identified by the carer assessment.	01 - Short breaks or respite 02 - Advice and information 03 - Practical support (e.g. transport, equipment/adaptions) 04 - Counselling or emotional support 05 - Training and learning 06 - Advocacy services 07 - Personal assistant/ support worker/community nurse, etc. 08 - Help from family, friends or neighbours 09 - Carer's allowance 10 - Other 11 - No help/support required	Only required if CAComplete = Yes - must be provided for all of these records.  Multiple responses possible.  All support needs identified should be included, not just those for which the carer is eligible for support.  Provides information on carer's support needs (Carers Act S9(1)(f)), and if support should be provided in the form of a break from caring (S9(1)(k)).
CASuppNeedsOther	Other support needs not included in list of options for CASupportNeeds	Free text	Only required if CASupportNeeds = 10.

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Variable Name	Description	Format/Values	Additional information
CASupportProv	The support that the local authority provides or intends to provide to the carer. This includes support arranged through other bodies e.g. local advocacy service, carers centre, etc	01 - Short breaks or respite 02 - Advice and information 03 - Practical support (e.g. transport, equipment/adaptions) 04 - Counselling or emotional support 05 - Training and learning 06 - Advocacy services 07 - Personal assistant/support worker/community nurse, etc. 08 - Help from family, friends or neighbours 09 - Carer's allowance 10 - Other 11 - No help/support required	Only required if CAComplete = Yes - must be provided for all of these records.  Multiple responses possible.  Provides information on the support provided to the carer (Carers Act S9(1)(i/j)), and if support will be provided in the form of a break from caring (S9(1)(k)).
CASuppProvOther	Other support that the local authority provides/intends to provided to the carer.	Free text	Only required if CASupportProv = 10.

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Variable Name	Description	Format/Values	Additional information
CARReviewOutcome	If the carer assessment was a review, has the assessment resulted in a change to the support provided?	1 - Yes 0 - No	Only required if CAComplete = Yes and CAType = Review  To provide information on the number/ proportion of reviews that result in a change to support.
CARReviewCrit	What conditions need to be met to trigger a review/reassessment?	(To be determined)	Only required if CAComplete = Yes - must be provided for all of these records.  (Multiple responses possible?)  Provides information on what will trigger a review (Carers Act S9(1)(l)).

## Carers Census 2017

### Additional data for YCS

Responsible authority/responsible local authority can be different for young carers. The responsible authority is the local authority in which the child resides (health board instead of LA for pre-school children), with some exceptions (Section 20 of the Act). Responsible local authority is the LA in which the cared-for person resides.

Variable Name	Description	Format/Values	Additional information
RespAuthority	The responsible authority for the young carer		Likely to be the same as the responsible local authority (LocalAuthority field) in most cases. Free text field, as this could potentially be a local authority, health board or school (so there are many possible options).
AppCare	The extent to which the responsible authority feels that the care provided by the young carer is appropriate.	?? (to be determined)	Carers Act S15(1)(c)

# Carers Census 2017

## Annex - Description of client groups

### 1 - Dementia

Global deterioration of intellectual functioning. Normally a progressive condition resulting in cognitive impairment ranging from some memory loss and confusion to complete dependence on others for all aspects of personal care. Exclude confusion due to other causes e.g. medicines, severe depression. Does not have to have been medically diagnosed.

### 2 - Mental Health Problems

Mental health problems are characterised by one or more symptoms including: disturbance of mood (e.g. depression, anxiety), delusions, hallucinations, disorder of thought, sustained or repeated irrational behaviour.

Include: persons assessed as having mental health problems whether or not the symptoms are being controlled by medical treatment.

Exclude: alcohol or drug related problems; dementia.

### 3 - Learning Disability

A significant, lifelong condition which has three facets: 1) significant impairment of intellectual functioning resulting in a reduced ability to understand new or complex information; 2) significant impairment of adaptive/social functioning resulting in a reduced ability to cope independently; and 3) which started before adulthood with a lasting effect on the individual's development.

### 4 - Physical Disability

Physical disabilities have many causes in chronic illness, accidents, and impaired function of the nervous system, which, in particular physical or social environments, result in long term difficulties in mobility, hand function, personal care, other physical activities, communication, and participation.

Include: visual impairment, hearing impairment, severe epilepsy; limb loss; severe arthritis; diseases of the circulatory system (including heart disease); diseases of the central nervous system (e.g. strokes, multiple sclerosis, cerebral palsy, spina bifida and paraplegia).

Visual impairment. Blindness or partial sightedness (unless problems resolved by spectacles or contact lenses).

Hearing impairment. Profound or partial deafness and other difficulties in hearing (unless problems resolved by a hearing aid).

Exclude: Acquired brain injury (code as 98); Problems arising from infirmity due to age (code as 8)

# Carers Census 2017

## 5 - Addiction

Alcohol-related problems - Any person who experiences social, psychological, physical, or legal problems related to intoxication and/or regular excessive consumption and/or dependence as a consequence of his/her use of alcohol.

Drugs-related problems - Any person who experiences social, psychological, physical or legal problems related to intoxication and/or regular excessive consumption and/or dependence as a consequence of his/her use of drugs or chemical substances.

## 6 - Palliative care (as defined by the World Health Organisation)

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. See <http://www.who.int/cancer/palliative/definition/en/> for full definition.

## 8 - Problems arising from infirmity due to age

This category should only be used for clients aged 65 and over.

## 98 - Other vulnerable groups

Clients should be included in this client group if they do not fall under the other categories for example clients with HIV/AIDS.

Acquired brain injury - Multiple disabilities acquired after birth arising from damage to the brain through head injury, stroke, lack of oxygen, infection, or other causes. People with an acquired brain injury usually have a complex mixture of physical, cognitive, emotional, and behavioural, disorders or difficulties. This may affect how the person perceives the world and their abilities to remember, concentrate, reason and judge. The person's emotional state may be disturbed; personality, behaviour, communication and relationships are also frequently altered. Mobility, sensation, vision, hearing and balance, smell and taste, respiration, heartbeat, and bowel and bladder control may also be affected.

## 99 - Not known

If it is not known whether the person has been given a client group.